

Posters

13. Psychosocial issues

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278 Developing patient resources for lung transplantation

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Aims: With advances in medical treatment, people with CF are living longer. However, CF remains a life-limiting condition with lung transplantation as a treatment option as health declines. To improve care of patients, patient resources were developed to improve patient understanding of the transplant process and optimise pre-listing counselling.

Methods: Three patient information resources were developed.

1. Transplant information leaflet: containing clear basic information about the transplant process itself and how this decision is made, and a discussion of the potential psychological dilemmas that people face and support available.
2. Post-transplant patients and CF MDT team members developed a document based on patients' experiences on the transplant ward, highlighting differences between their regular ward in the CF Centre and the ward at the transplant centre. This is particularly important for patients with CF who are 'expert patients' and are often very involved in their own treatments and treatment choices.
3. 'This is me' leaflet which patients complete and take to the transplant centre. This contains key information, including contact details and non-medical information, which will help the people caring for them at transplant.

Conclusion: These resources aim to ensure that all CF patients are informed about the lung transplantation process and that those undergoing assessment and listing are prepared for differences in their care in the transplant clinic/ward, making the process less distressing for patients who are already in a very stressful situation.

279 Proposal of a questionnaire for cystic fibrosis patients who have just been transplanted to ensure their safety before the first return home after transplantation

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Objectives: After lung transplantation, cystic fibrosis patients have a lot of new skills to acquire and some are essential for patient's safety, particularly before the first return home.

Methods: In 2009, we elaborated a referential of skills, both for the immediate post-operative period and the long-term follow-up (ECFS Dublin 2012). We identified in the list twenty essential objectives that must be acquired by all patients, during educative sessions. Generally, patient education begins around the 15th day after transplantation, after the reanimation period. Patients begin to ask questions about their new medications, diet, hygiene etc. About fifteen days later, patients are ready to go back home for the first time, it is the moment to assess that they have reached all the essential objectives. For that, we built a questionnaire which includes 9 True/False questions with degrees of certitude and four multiple-choice questions. Questions essentially relate to the modalities of taking medications, adherence to treatment, the emergency situations but also the prevention. The multiple-choice questions relate to their daily life.

Results: Patients must correctly answer the questions before they first return home. In case of errors, new educative sessions will be organized to ensure patients' safety. The questionnaire is now used in most French transplantation units. Both patients and health-care givers are satisfied.

Conclusion: The safety of recently transplanted patients for cystic fibrosis before the first return home can be assessed by a short questionnaire. It is easy to fill and can be quickly analyzed by health-care professionals.

280 VEMSE-CF: psychosocial characteristics of patients participating in a prospective controlled care research study

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Objectives: Cystic Fibrosis (CF) care requires a multi-professional team approach including psychosocial services. VEMSE-CF is a comprehensive care program integrating medical and psychosocial interventions. To determine the specific needs for supportive psychosocial interventions all patients were screened for co-morbid behavioral and emotional symptoms.

Methods: 151 CF-patients 6-years or older were recruited in three CF-out-patient clinics and will be followed up for two years. Patients from other CF centres receiving usual care and matched for sex, age and lung-function were identified as controls. At the time of recruitment, patients 6–13 years were screened with the Strengths and Difficulties Questionnaire (SDQ parent form) and patients ≥14 years were screened with the Hospital Anxiety and Depression Scale (HADS).

Results: The baseline characteristics for the 151 participants in the intervention group (73 female; FEV-1 % pred.: 70.3±27.3; Median BMI: 19.2) suggest that a cohort representative of the German CF-population has been selected. Among 48 pediatric patients with CF, 20.9% showed elevated symptoms on the problem score of the SDQ. Among 98 adolescent and adult patients, 30.6% showed elevated symptoms of anxiety and 18.4% showed elevated symptoms of depression.

Conclusion: Between 20 and 30% of the study participants showed elevated behavioral and/or emotional symptoms at baseline and were offered additional psychosocial care within the program. Follow-up assessments will evaluate the effect of the comprehensive care model on psychosocial outcomes.

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281 Patient-centered outcomes in CF research

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Objectives: Identify the core patient-centered outcomes in CF research.

Methods: Italian Patient Centered Outcomes Research (IPaCOR: 12 clinical researchers and 8 expert CF stakeholders) researchers under the supervision of a methodologist identified and classified all the outcomes from the 72 Cochrane reviews in CF. A list of outcomes was created and thoroughly discussed among all clinical researchers and CF stakeholders in 4 meetings and via e-mail. Clinical researchers and CF stakeholders independently ranked the entire list of outcomes with respect to relevance using a score from 1 (very low) to 9 (very high).

Results: The 72 Cochrane reviews were divided into 10 research areas and produced a list of 206 outcomes (taking into account synonyms). Clinical researchers tried to classify this list creating for each outcome (e.g. DIOS) a category (e.g. clinical), a subcategory 1 (e.g. gastroenterology) and a subcategory 2 (e.g. symptoms/conditions/complications). With respect to patient centered relevance CF stakeholders and researchers agreed about relevance only for 46/206 outcomes (22%) while 23/206 (11%) and 25/206 (12%) outcomes are considered not relevant by researchers and by stakeholders respectively. For 113/206 (55%) outcomes CF stakeholders and researchers didn't agree about the relevance.

Conclusion: There are marked differences in the perception of relevance for each outcome by clinical researchers and CF stakeholders. The results of the IPaCOR's outcome ranking method suggests the need to re-classify the outcomes by taking into account the patients' perspective.